How Parental HIV Affects Children

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The shadow cast by HIV reaches beyond individuals diagnosed with the condition. It touches the lives of family members, friends, coworkers, and many others. One group in particular that feels these effects keenly is the children of HIV-positive parents. With improved treatments that have extended the life expectancies of HIV-infected people and prevented transmission during pregnancy, the number of children with an HIV-infected parent is expected to grow.

An emerging body of research conducted by RAND and several collaborating institutions has shed light on the problems confronting this population and has provided a policy perspective for addressing them. Like other children with a seriously ill parent, HIV-affected children are vulnerable to emotional and behavioral difficulties. However, the research shows that they also face unique challenges specifically related to their parents' HIV status, including misconceptions about transmitting HIV, fear of prejudice and discrimination, family disruption, and lack of planning for their future care. The research also indicates ways in which clinicians and other institutions that provide support can help to address some of the negative effects of parental HIV on children.

The studies are based on data from the HIV Cost and Services Utilization Study (HCSUS), the first comprehensive U.S. survey of HIV-infected individuals using a nationally representative sample. Participants in HCSUS were at least 18 years old, had known HIV infection, and had visited a medical provider during the first two months of 1996. They were surveyed three times from January 1996 through January 1998. HCSUS remains the only nationally representative data set of people receiving medical care for HIV in the contiguous United States. HCSUS conducted interviews with 2,864 adults with HIV, of which 28 percent reported having at least one child under 18 years old. This research brief summarizes the main results of studies in which researchers analyzed the HCSUS data on how parental HIV affects children, as well as new data collected in 2004–2005 via qualitative interviews with a subset of 33 previous HCSUS participants and their family members.

Key findings:

- One-quarter of HIV-infected parents avoided common physical interactions with their children "a lot" due to misconceived fears of transmitting HIV. Some children expressed legitimate fears about transmission through blood, but also misconceived fears about transmission through generally harmless activities such as sharing food and kissing or hugging.
- Just over half of parents were reluctant to disclose their HIV, fearing their children would tell others and experience discrimination; such fears limited opportunities for social support.
- Many children did not remain in their parents' custody, and few unmarried parents had prepared legal guardianship plans.

Fear of Transmission Can Limit Parent-Child Interactions

Few studies have examined the extent to which families with an HIV-infected parent fear transmission of the disease and how such families cope with these fears, nor have they examined the extent to which fear of transmission may limit parent-child interactions and also who might be at greatest risk of avoiding interactions. A paper published in 2005 (Schuster et al.) provided answers to some of these questions based on interviews with HIV-infected parents. The authors found that 42 percent of these parents feared catching opportunistic infections from

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their children, and 36 percent feared transmitting HIV to the children.

In terms of *avoiding interaction* with their children due to these fears, more than one-quarter of the parents (28 percent) said that they avoided some form of interaction "a lot." By including parents who avoided physical interaction "a little" due to these fears, the overall avoidance rate increased to 40 percent. Few parents reported that they avoided kissing on the cheek or hugging, but many more avoided kissing on the lips or sharing utensils, even though HIV is not transmitted through these modes. The authors concluded that while it is encouraging that parents rarely withheld the most routine forms of affection, it is of concern that more than one-quarter of them restricted their interactions a lot because of fears of contagion. Table 1 presents these findings in more detail.

Hispanic/Latino parents, especially those interviewed in Spanish, were more likely than parents from other racial or ethnic groups to report avoiding interactions because of their fears. Fathers were more fearful of transmitting HIV to their children than mothers were. Based on the findings, the authors advise that more work may need to be done to inform parents and their children about the possible modes of HIV transmission.

A related qualitative analysis, published in 2008 (Cowgill et al.), identified similar transmission-related fears, based on input from children and other family members as well as HIV-infected parents. Participants included 33 HIV-infected parents who were a subset of original HCSUS participants, 27 minor children (9–17 years old), 19 adult children, and 15 caregivers (spouses/partners, grandparents, or friends). Parents and children were interviewed privately using open-ended questions to obtain detailed descriptions of family members' experiences.

About two-thirds of families in the study expressed fears about HIV transmission in their households. Commonly, these were well-grounded fears about transmission through blood contact, but some fears were based on misconceptions about transmission through bathroom items, kissing or hugging, and food. HIV-infected parents were most concerned about exposing children to their blood, and both children and parents had vivid memories of the tension surrounding incidents in which parents had cut themselves. Children expressed similar concern about transmission through blood contact but also through generally harmless daily activities, such as sharing plates of food or hugging and kissing their parents (see Table 2). Parents also had realistic concerns

Table 1
Avoidance of Parent-Child Physical Interactions

Variable	Percentage of Parents Reporting
Avoidance of specific activities a lot because of fear of transmitting HIV to child	
Kissing child on lips	19
Sharing utensils with child	15
Hugging child	1
Kissing child on cheek	1
Any of the above	25
Avoidance of specific activities a lot because of fear of becoming infected with illness from child	
Kissing child on lips	16
Sharing utensils with child	13
Hugging child	1
Kissing child on cheek	1
Any of the above	19
Overall rate of avoidance of the above activities	
A lot	28
A little or a lot	40
NOTE: Results are based on interviews with 344 parents who are HIV-positive.	

Table 2
Comments from HIV-Affected Children About Transmission-Related Fears

Respondent	Transmission-Related Fear
Adult daughter recalls incident when she was younger and her HIV+ mother cut herself	"She [the HIV-positive mother] was bleeding and my first reaction was to run toward her. She literally pushed me really hard away from her. She said, 'Don't come near me!'… And that was when it was so like real to me and I just, I don't even know what I felt, but I felt like a whirlwind of emotions."
16-year-old girl describes her HIV+ mother's fear about kissing on the lips	"Let's say I come home, I always kiss my mom on the cheek or whatever. You know…certain kids; they kiss their mom on the lips and stuff. My mother doesn't like to do that. I don't know why…she's just careful about everything."
15-year-old boy explains how he kisses his HIV+ mother	"Kissing my mother…not on the lips…on the cheek and stuff. So I don't worry."
16-year-old girl expresses uncertainty about sharing a cup with her HIV+ mother	"They [parents] are always being cautious with us. Like, you know, about cups and don't use the stuff [the parent] uses. It's always been a question mark there."
Adult daughter recollects concern about mother catching an opportunistic infection from her	"There were lots of times where I would be drinking something out of a glass and she [HIV-positive mother] would come and take it and just drink from it and I wouldn't worry about catching something from her. I would worry that she would get sick from me—from me having a cold, or something."

about catching opportunistic infections from a sick child and about being able to safely care for a child with chicken pox, a cold, or the flu.

Families sometimes addressed these fears by educating children about their understanding (right and wrong) regarding modes of HIV transmission, by establishing rules, and by taking what they saw as necessary precautions to reduce the risk of HIV transmission. For example, in some households, children were instructed not to use their parent's bathrooms, toothbrushes, or razors, and not to share food or drink from the parent's cup. Children were also taught to avoid parents when they were bleeding until the injury was cleaned and dressed. Many families said they focused on personal hygiene and strove to maintain a clean household to reduce concerns about HIV transmission. In some instances, parents and caregivers dispelled myths about HIV transmission; in others, they perpetuated them. For instance, a 13-year-old girl purged herself after eating her HIV-infected mother's food because her extended family told her she would die if she ate her mother's cooking. The researchers concluded that clinicians treating HIV-infected parents and their children can play an important role by educating these families about how HIV is transmitted and how it is not.

Stigma Reduces Parents' Disclosure to Children and Limits Children's Opportunities for Social Support

HIV-related stigma can limit the ability of people with HIV and their families to cope with the illness by isolating them from sources of social support. In the same semi-structured interviews with 33 families discussed above (33 HIV-infected parents, 27 minor children, 19 adult children, and 15 caregivers), researchers investigated the extent to which (1) participants feared stigma, (2) parents with HIV actually experienced prejudice and discrimination, and (3) children and caregivers experienced prejudice and discrimination through association with the HIV-infected parent (Bogart et al., 2008). The interview protocol did not include direct questions about stigma; however, all families spontaneously discussed HIV stigma, which the authors attribute to the force with which stigma resonates in their lives. Table 3 indicates the different types of stigmatizing experiences spontaneously reported by participants in this study.

In all the families, at least one family member feared or experienced stigma.[1] Parents were afraid to disclose their HIV status to their children for fear that the children would disclose their parents' HIV status to others, who would then treat the children unfairly. When parents disclosed this information to children, they warned them about the possibility of prejudice and discrimination from extended family members, friends, and teachers. Consequently, children worried about experiencing stigma and tended not to tell their friends. While not telling their friends may have protected some of these children from experiencing stigma, it also may have isolated them, led to loneliness, and prevented them from obtaining social support from peers.

Table 3
Number of Respondents Who Reported Stigma, by Type of Stigma

Respondents	Feared Being Stigmatized	Victim of Prejudice or Discrimination	Victim of Stigma by Association
Mothers with HIV (n=24)	23	19	1
Fathers with HIV (n=9)	8	6	1
Children under 18 (n=27)	13	3	0
Adult children (n=19)	15	3	3
Caregivers (n=15)	9	3	5
Families (n=33)	32	26	10
NOTE: Thirty-three families participated in this analysis.			

At least one person in most of the families (26 of the 33 families) had experienced actual acts of discrimination and/or prejudicial attitudes. Extended family members and friends were the primary source of these incidents, which included complete avoidance, ostracism, and verbal insults. In general, much of this behavior seemed to arise from a fear of HIV infection and a lack of knowledge about the ways that HIV is transmitted. For example, HIV-infected parents reported that they were not allowed to hold their nephews or nieces and that family and friends would not eat food prepared by them or would discard plates that they had used. Some family members' and friends' initial fears about transmission changed over time after education about the disease.

In ten families, an uninfected family member or caregiver experienced stigma by association with the HIV-infected parent. Several of the adult children reported that they had lost friends during their younger years as a result of their parents' HIV status and that friends of caregivers would not come to their homes, fearing there might be contagion in the house.

An earlier analysis of HIV-infected parents from the HCSUS data set (Corona et al., 2006) found that 56 percent of children did not know their parents' HIV status, based on parent reports of such knowledge. Findings indicated

[1] When one factors in not only those families who feared being stigmatized but those who also experienced it, all 33 families were affected.

that parents who (1) had higher incomes, (2) had likely been infected through heterosexual intercourse, (3) were in better health, (4) experienced greater social isolation, and (5) had younger children were less likely to report that their child knew of their health status. As shown in Figure 1, chief among the reasons that parents gave for not disclosing their illness was fear of the emotional consequences of disclosure for the child (67 percent of parents). More than one-third of parents (36 percent) reported that their reason for nondisclosure stemmed from worry that their child would tell others.

In this study, parents reported that 5 percent of children who were aware of their parents' HIV had experienced other children not wanting to play with them, 9 percent had been teased or beaten up, and 11 percent worried about catching HIV from their parent. However, parents also reported that 14 percent of children over age 9 had received emotional support from other children.

Loss of Custody and Lack of Guardianship Planning Can Lead to an Unstable Future

HIV-infected parents may have difficulty maintaining custody of their children while coping with the disease, but children removed from their parents' custody may be subject to added behavioral and emotional problems. To better understand why HIV-infected parents retain or lose custody of their children, the authors of a paper published in September 2007 used the HCSUS data set to determine the rates and predictors of child custody status (Cowgill et al.). The authors found that more than half of the children in the study were not in their parents' custody at some time during the two-year study period, highlighting the instability faced by many of these children. Parents cited drug use (62 percent), financial hardship (27 percent), HIV status and associated illness (10 percent), and mental illness (10 percent) as reasons for losing custody of their children.

The authors found that, during the study period, children were less likely to be in the custody of HIV-infected fathers, older parents, and parents living without other adults than of HIV-infected mothers, younger parents, or parents living with other adults. When their parents lost custody, children often lived with extended family members, such as grandparents.

In a related analysis using the HCSUS data set, researchers examined rates and predictors of guardianship planning and preferred guardians (Cowgill et al., February 2007). The authors found that slightly less than 30 percent of the unmarried parents had prepared legal documentation of a guardianship plan for their children. Twelve percent of parents had not identified a guardian; 6 percent had, but had not discussed their preference with the guardian; 53 percent reported their preferred guardian had agreed but that no legal document formalized the agreement; and 28 percent had prepared legal documentation of their guardianship plan. Parents who were in poorer health and parents living without other adults were more likely to have completed the guardianship planning process.

Figure 2 identifies the guardian preferences of parents in the study. Other biological parents, grandparents, and other relatives were most often identified as the guardian of choice.

Figure 1
Reasons for Nondisclosure

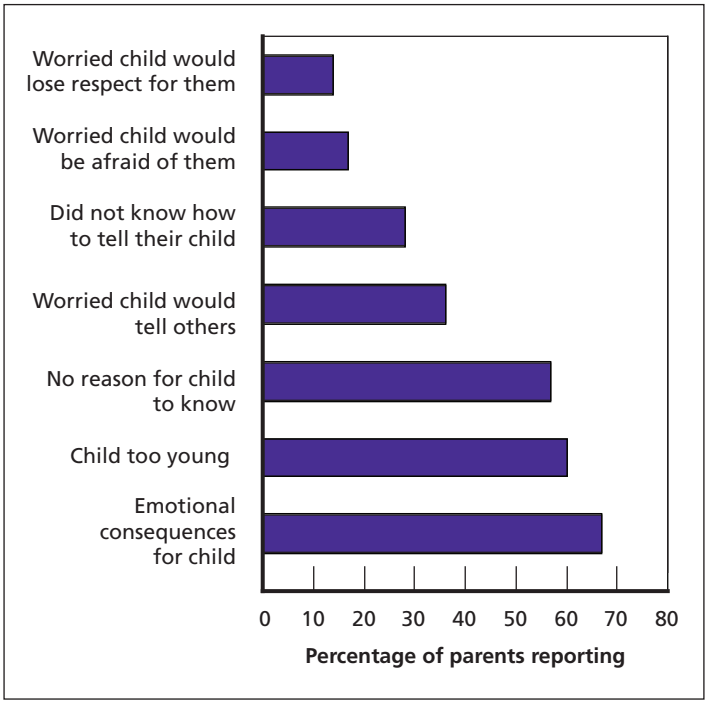
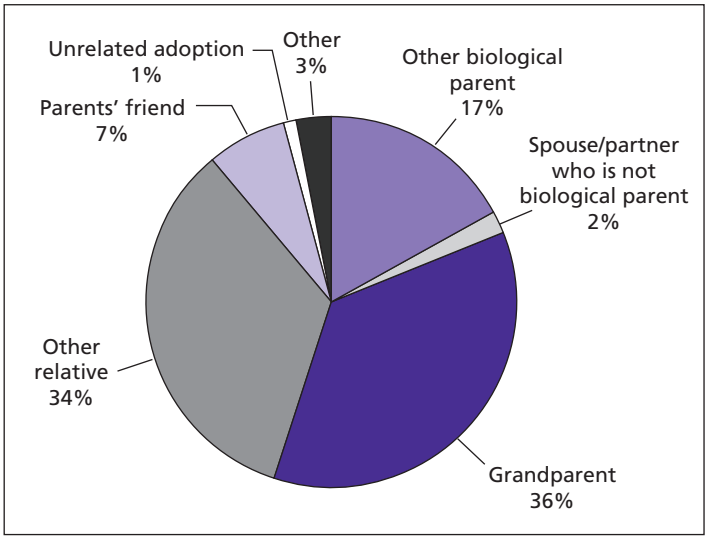


Figure 2
Unmarried HIV-Infected Parents' Preferred Choice for Child's Guardian



The authors provided several potential explanations for why HIV-infected parents did not have a formal guardianship plan for their children. Some parents may not have felt it was necessary to have a legal document for a guardian who was already a family member, like a grandmother or aunt. Other parents may have had difficulty finding someone willing to accept legal responsibility for their children. Additionally, HIV-related stigma, depression, distrust, and/or lack of understanding of the legal system may have contributed to parents' not having a formal guardianship plan in place.

Interventions from Common Sources of Support Could Help

Study authors recommended a number of interventions to assist HIV-infected parents and their children to better cope with the illness. For example, clinicians may be able to support and guide HIV-infected parents in deciding whether, when, and how to disclose their infection to their children. Clinicians are also in an excellent position to address misconceptions parents and other family members have about the transmission of HIV that could interfere with family interactions. Pediatricians and others taking care of children may be able to offer counseling or referrals to assist parents with child custody issues and for guardianship planning.

Researchers suggest a need for effective interventions to reduce HIV stigma and to support families coping with its harmful effects. Skill-building (through, for example, mock role-playing with HIV-positive individuals) holds promise in reducing HIV stigma. Support groups for children of HIV-infected parents would enable children to discuss their family situation in an accepting context. By connecting children with similar peers and families, support groups may help to reduce isolation and loneliness among children of parents with HIV. Media campaigns about HIV/AIDS could incorporate information to address the myths that continue to exist about how HIV is transmitted. ■

This Highlight summarizes RAND Health research reported in the following publications:

Bogart LM, Cowgill BO, Kennedy D, Ryan G, Murphy DA, Elijah J, Schuster MA, "HIV-Related Stigma Among People with HIV and Their Families: A Qualitative Analysis," *AIDS and Behavior*, Vol. 12, 2008, pp. 244–254.

Corona R, Beckett MK, Cowgill BO, Elliott MN, Murphy DA, Zhou AJ, Schuster MA, "Do Children Know Their Parent's HIV Status? Parental Reports of Child Awareness in a Nationally Representative Sample," *Ambulatory Pediatrics*, Vol. 6, No. 3, May–June 2006, pp. 138–144.

Corona R, Cowgill BO, Bogart LM, Parra MT, Ryan G, Elliott MN, Park SK, Patch J, Schuster MA, "Brief Report: A Qualitative Analysis of Discussions about HIV in Families of Parents with HIV," *Journal of Pediatric Psychology*, Vol. 34, No. 6, July 2009, pp. 677–680.

Cowgill BO, Beckett MK, Corona R, Elliott MN, Zhou AJ, Schuster MA, "Children of HIV-Infected Parents: Custody Status in a Nationally Representative Sample," *Pediatrics*, Vol. 120, No. 3, September 2007, pp. e494–e503.

Cowgill BO, Beckett MK, Corona R, Elliott MN, Parra MT, Zhou AJ, Schuster MA, "Guardianship Planning Among HIV-Infected Parents in the US: Results from a Nationally Representative Sample," *Pediatrics*, Vol. 119, No. 2, February 2007, pp. e391–e398.

Cowgill BO, Bogart LM, Corona R, Ryan G, Schuster MA, "Fears About HIV Transmission in Families with an HIV-Infected Parent: A Qualitative Analysis," *Pediatrics*, Vol. 122, No. 5, November 2008, pp. e950–e958.

Schuster MA, Beckett MK, Corona R, Zhou AJ, "Hugs and Kisses: HIV-Infected Parents' Fears About Contagion and the Effects on Parent-Child Interaction in a Nationally Representative Sample," *Archives of Pediatrics & Adolescent Medicine*, Vol. 159, No. 2, February 2005, pp. 173–179.

Schuster MA, Kanouse DE, Morton SC, Bozzette SA, Miu A, Scott GB, Shapiro MF, "HIV-Infected Parents and Their Children in the United States," *American Journal of Public Health*, Vol. 90, No. 7, July 2000, pp. 1074–1081.

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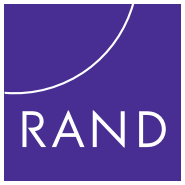

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